Seminar Transcript

Lionel D C Hartley

This page intentionally blank

Surviving and Thriving with Cancer
(Seminar Transcript)
Condensed from Dr Hartley's book "Surviving and Thriving with Cancer" (1989)
Lionel Hartley, PhD
Published by L&R Hartley
Copyright ©2014 Lionel Hartley
All rights reserved in all countries.
No part of this book may be used or reproduced in any manner whatsoever without written permission except in the case of brief quotations embodied in critical articles and reviews.
Typeset in Times New Roman and Arial

This page intentionally blank

Surviving and Thriving with Cancer

SEMINAR TRANSCRIPT

Slide 1 Title Slide

Slide 2 Video clip 1

Slide 3 Who is your seminar author

Everyone with cancer copes in his or her own way. The diagnosis may cause you to feel a range of strong emotions, such as fear, anger, disbelief, sadness, guilt, loneliness, loss of control or distress.

Although each of us has our own way of coping, these are all natural reactions to such

significant life-changing news. A cancer diagnosis can also affect relationships with family, friends and carers, so this seminar will provide practical tips about how to talk to others about your diagnosis, your treatment and how you're feeling.

You'll find some suggestions for working together to adjust to

these challenges.

I also have information for people caring for someone with cancer.

It is important to remember that there is no right or wrong way to feel when you are faced with cancer - just as there is no one right way to cope.

Hopefully, this seminar will remind you of the things you are doing well and to give you some fresh ideas for facing the future.

It is often difficult to take in a diagnosis immediately - you might hear the words but not believe them.

There are many

reasons for this shock: cancer is a serious disease, and most people feel afraid and unsure about treatment, side effects and the likely impact on family and work.

Cancer can also feel like a threat to your way of life. You may wonder if you will be the same person as before, if you will be able to do the

things you usually do and if your relationships will change.

Having these thoughts and feelings is a natural reaction to a difficult situation. Knowing this can help you find ways to manage these feelings.

Over time, you may find that your strong feelings about cancer fade. Although your life has changed in some ways,

in other ways it goes back to a more regular pattern and you feel more or less like your usual self.

However, this may not happen, instead you may continue to feel worried and upset and these feelings can interfere with your life.

Slide 4 Dealing With The Diagnosis

Common reactions

For many people, the first few weeks after they are diagnosed with cancer are very stressful. You may have trouble thinking clearly, eating or sleeping. This can last from several days to several weeks. It's

common to feel that you are on an emotional roller coaster.

Feelings you may experience

Fear

It's frightening to hear you have cancer. Most people cope better when they know what to expect.

Anger

You may feel angry with health care professionals, your God, or even yourself if you think you may have contributed to the cancer or a delay in diagnosis.

Disbelief

You may have trouble accepting that you have cancer, especially if you don't feel sick.

It may take time to

accept the diagnosis.

Sadness

It is natural for a person with cancer to feel sad. If you have continual feelings of sadness, and feel sleepy and unmotivated - talk to your doctor - you may be clinically depressed.

Guilt

It is common to look for a cause of cancer. While

some people blame themselves, no-one deserves to get cancer.

Regret

Cancer survivor Donald Hall in an article entitled *'Life Work'* wrote, "For weeks after my last operation - frail and without energy, sleeping 10 hours - I looked in my house at all the books I had not read and wept for my inability to read

them. Or I looked at great books I had read too quickly in my avidity - telling myself I would return to them later. There is never a later, but for most of my life I have believed in later.

Loneliness

It's natural to feel that nobody understands what you're going through.

You might feel lonely and isolated if your family and friends have trouble dealing with cancer, or if you are too sick to work or socialise with others and enjoy your usual activities.

Loss of Control

Being told you have cancer can be overwhelming and make you feel as though you are losing control of your

life.

Distress

Many people, including carers and family members, experience high levels of emotional suffering as a direct result of a cancer diagnosis.

Worry

After diagnosis the next step is likely to be treatment - which could

be one event, such as surgery, or a series of events such as surgery, chemotherapy and radiotherapy.

Each of these will have its own demands, including medical appointments, tests, physical and emotional side effects, and changed routines.

While it can be useful to plan for what lies ahead,

worrying about the future can make you feel even more distressed. Instead, try to focus on the most immediate concern, directing your effort where it is needed right now.

After you have dealt with what is happening now, you can then face the next step.

Try to take advantage of the breaks between

treatments, tests or appointments, or when you are less troubled by the effects of your treatment.

These breaks give you a chance to recharge, both physically and emotionally.

If you are having trouble dealing with any of your emotions, consider

talking to family and friends, seeking professional help through a counsellor, psychologist or psychiatrist, or joining a support group.

A patient, I'll call her Elisa, said, "Some mornings I would wake up feeling like I didn't even want to get out of bed, that real 'down in

the dumps' feeling. But once I got started, that feeling would kind of lift and things would seem okay."

Slide 5 Finding Hope

Having cancer doesn't mean you have to lose hope. The outlook for many cancers is improving constantly.

Some cancers can be treated successfully, while others can be controlled.

If the cancer can't be controlled, symptoms can be relieved to make life

more comfortable. It is still possible to live well.

Often the first thing people ask when they are told they have cancer is, 'Am I going to die?'.

Talk to your doctor about what the diagnosis means for you and what the future may hold.

Knowing more about your illness may help ease this fear.

Slide 6 Promote Depression Seminar

Many people feel low or depressed after a cancer diagnosis, during treatment or when they are recovering. Don't be surprised if you feel unhappy at times.

But there is a difference between feeling unhappy and being depressed. You may be depressed if

you are in a low mood for most of the time, or have lost interest and pleasure in most things for more than two weeks.

Depression often won't go away by itself, but tackling it early may mean that you can deal with problems quickly and avoid symptoms becoming worse.

There are also many effective treatments for

depression, including both medication and non-medication options.

Slide 7 Physical Effects

The physical effects of cancer and cancer treatments may affect your emotions in different ways.

People who experience physical symptoms, such as fatigue, nausea and pain, are often more likely to have emotional distress. How long these physical effects last

varies from person to person.

Fatigue

Feeling exhausted and lacking energy for day-to-day activities (fatigue), is the most common side effect of cancer treatment. It can be caused by the physical and emotional effects of diagnosis and treatment.

Fatigue differs from normal tiredness as it often doesn't go away with rest or sleep.

Fatigue can also be linked to low moods or depression, so it may help to talk to a health professional about available treatments.

Combating Fatigue

Schedule
Exercise
Sleep patterns
Naps
Fresh Air

o Plan to do things at the time of day when your tiredness is least severe.

Keeping a journal may help you keep track of your 'good times'.

- Research shows that gentle exercise reduces tiredness, helps preserve muscle strength and gives a sense of normality.

- Let your doctors or nurses know if you are having trouble sleeping.

- Have a short rest during the day. Naps can refresh you without making it hard for you to sleep at night.

o Try to spend some time outside in the fresh air each day.

Slide 8 Physical effects:

(Shaded) Physical effects: Fatigue

Physical effects: Pain

People can experience pain from cancer and its treatment. If you are feeling anxious, this can make pain more difficult to handle. If you are in pain, discuss it with your doctor. There are many

treatments now available to help relieve pain.

Physical effects: Loss of appetite

You may not feel like eating if you are unwell, stressed or experiencing the physical effects of cancer treatment.

You may also lose your appetite if you're anxious or depressed. This may cause you to lose weight

and strength.

Good nutrition, or giving your body the food it needs to keep working properly, can help you cope better with the effects of cancer and treatments.

It can give you more energy, make you feel less tired, and maintain your wellbeing.

Cancer survivor Pete says, "I found the decision to take morphine regularly difficult. Having made it, I have been taking the slow-release tablets for 18 months with no appreciable side effects. Without the morphine, the pain would be too debilitating for me to continue doing all the things I do now."

Slide 9 Physical effects:

(Shaded) Physical effects: Fatigue

(Shaded) Physical effects: Pain

Physical effects: Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem).

You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

Cancer treatments,

such as chemotherapy and radiotherapy, can sometimes cause side effects such as hair loss and skin irritation. These changes can make you feel self-conscious.

Slide 10 Promote Self Esteem Seminar

Slide 11 Sexuality, Intimacy and Cancer

Sexuality is about who you are and how you feel as a man or woman. It is the feelings and characteristics that make up your sexual identity. This means different things to different people.

Having cancer can

affect your sexuality in both physical and emotional ways.

The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, the way you see your changed body, and your self-confidence.

Knowing the potential

challenges and addressing them may help you adjust to these changes.

While sexual intercourse may not always be possible during and immediately after treatment, closeness and sharing can still be part of your relationship.

If sex is painful, or you have doubts about the

safety of sexual activity, check with your doctor. Counselling, either individually or together, can provide ways to discuss cancer and how it affects your relationship with your partner.

Intimacy isn't all about sex. Sexual intercourse (or penetrative sex) is not the only way of showing love and affection or expressing sexual

feelings.

Holding, cuddling, kissing and caressing are also important ways of being intimate.

I have a handout, "Sexual Confidence After Cancer", that may be useful if you or someone that you know has or is likely to have problems in this area.

Slide 12 Your Coping Toolbox

Most of us have different ways of coping with difficult situations that we have learned over a lifetime.

These could include:

o Seeking more information

o Trying to fix the problem

- Having a laugh to feel better
- Distracting ourself from unhelpful thoughts and feelings
- Talking things through to try and make sense of what is happening
- Denying the circumstances.

How we cope depends on the type of situation

we are facing, our personality, upbringing, role models and what has worked in the past.

We might find our usual ways of coping are not enough to handle the different challenges caused by cancer.

There is no single best or right way of coping, but having a few different ways at your disposal may help you feel a

greater sense of control and confidence.

Think of ways of coping as being tools in your toolbox. Different jobs generally need different tools. If one tool doesn't fit the job, you need to try another one.

It's helpful to consider several strategies or 'tools' for coping with a cancer diagnosis and treatment.

Some strategies are generally unhelpful for any situation if used too much, such as, avoiding the problem entirely, self-blame, alcohol or drug use, overeating, or gambling.

Here are some tools to help you cope:

Slide 13 Your Coping Toolbox

1. Gathering information

Once diagnosed, there is a lot of information to take in - and well-meaning family and friends may give you even more.

Too much information may leave you confused about what to do. Instead, you may need

more accurate information or a way of dealing with what you already have.

If you are unsure or confused about certain information, it can help to talk to your doctor.

Doctors are usually happy to explain things and point you in the right direction.

Consider writing your

questions down beforehand so you remember what you want to ask when you see your health care professionals.

Slide 14 Your Coping Toolbox (Cont.)

2. Organise and update your affairs

Many people with cancer review their

insurance policies and update their will. This doesn't mean you have given up.

Everyone needs to do these things and once done you will have less to worry about.

It can help to take a close family member or friend to consultations with your doctor to take notes, ask questions and to help you remember

the information you are given.

Slide 15 Your Coping Toolbox (Cont.)

3. Looking after yourself

Cancer can cause physical and emotional strain. Some days you may feel better than others.

Nurturing yourself can enhance your wellbeing

and reduce stress during this time.

Eat well

Eating well gives your body better fuel to help it cope with the stress of illness and treatment.

Be active

Physical activity has been shown to lift mood, lower blood pressure, improve sleep and reduce stress. It is also

an important way to manage fatigue - helping you to feel more energetic and less tired. Even a short walk daily can help.

Slide 16 Your Coping Toolbox (Cont.)

4. Make time for yourself

Even though life may be very busy, it is important

to make time each day just for relaxation and enjoyment.

Think about things you do (or have done in the past) that help you to relax and feel good.

Slide 17 Your Coping Toolbox (Cont.)

5. Deal with feelings

Blocking out or avoiding your emotions may

create extra pressure, leading to increased frustration and anxiety.

Talking about the problem with your partner, friends, or members of your cancer care team may be more effective and less tiring, helping to make sense of your feelings as well as lighten your load.

You can also call the Cancer Helpline on

13 11 20 to talk about your issues confidentially.

Slide 18 Your Coping Toolbox (Cont.)

6. Sort out issues

A cancer diagnosis may happen in the context of other life stresses such as financial problems, work-related issues, relationship concerns and family stresses.

Dealing with other sources of stress in your life may help you cope better with the additional burden of cancer treatment.

Slide 19 Your Coping Toolbox (Cont.)

7. Sort out priorities

Author James S. Hewett tells of Paul Tsongas. Paul was a young and

rising member of the U.S. Senate.

Learning he had cancer made him re-evaluate the time he had been spending with his wife and children, compared with the time he spent at work.

After spending a rare evening at home with them, he realized that with the schedule he was keeping, the next night

like this would probably be several years in the future.

After this sobering realization he made this observation: "Nobody on his deathbed ever said, 'I wish I had spent more time on my job.'"

Slide 20 Your Coping Toolbox (Cont.)

8. Stay connected

Staying connected with the world through work, hobbies, or time spent with family and friends, may help you see a life outside of cancer and provide time out from your worries.

Slide 21 Your Coping Toolbox (Cont.)

9. Tap into spiritual beliefs

Some people find meaning and comfort from their faith and spiritual practices, such as meditation or prayer. Others may experience spirituality more generally. For some people the experience of cancer challenges their beliefs. It may help to talk to a spiritual leader or pastoral care worker about your feelings.

Slide 22 Your Coping Toolbox (Cont.)

If you have a belief system, listen to this anonymous observation:

Cancer is so limited.

Cancer cannot cripple love,

Cancer cannot shatter hope,

Cancer cannot corrode faith,

Cancer cannot eat away peace,

Cancer cannot destroy confidence,

Cancer cannot kill friendship,

Cancer cannot shut out memories,

Cancer cannot silence courage,

Cancer cannot reduce eternal life,

Cancer cannot quench the Spirit,

Cancer cannot lessen the Power of the resurrection.

-o0o-

One man in his late twenties told of the distress of the previous year when his wife had undergone a double mastectomy because of

cancer.

From diagnosis through surgery and on to the present, he had struggled to remain strong for his wife, wanting to be a source of encouragement for her.

But his own pain, confusion, and fear were nearly crippling him emotionally.

He shared that during

this time there were nights when sleep would not come, nights when - sometimes with his wife, sometimes alone, but always with tears - he would read the words of a very short psalm: Psalm 142.

Psalm 142 - "A Prayer when David was in hiding in cave. I cried unto the Lord with my voice; with my voice unto the Lord

did I make my supplication. I poured out my complaint before him; I showed before him my trouble. When my spirit was overwhelmed within me, then thou knewest my path. In the way wherein I walked have they privily laid a snare for me. I looked on my right hand, and beheld, but there was no man that would know me: refuge failed me; no man

cared for my soul. I cried unto thee, O Lord: I said, Thou art my refuge and my portion in the land of the living. Attend unto my cry; for I am brought very low: deliver me from my persecutors; for they are stronger than I. Bring my soul out of prison, that I may praise thy name: the righteous shall compass me about; for thou shalt deal bountifully with me."

Slide 23 Your Coping Toolbox (Cont.)

10. Recognise signs of stress and anxiety

Your body releases adrenaline, your heart beats faster, your blood pressure goes up, your breathing is shallow and fast, your hands get sweaty, and your mouth gets dry. These are natural responses and useful when dealing with

emergencies, but not very helpful in dealing with cancer.

Slide 24 Your Coping Toolbox (Cont.)

11. Notice your thinking

This is not always easy because thoughts are often quick and auto-matic. When you are feeling upset, it may help to stop and take note of

the thoughts going through your mind.

Write down your thoughts

Writing down your thoughts is helpful because it slows down your thinking and makes it easier to focus.

Check your thoughts

If your thoughts are making you feel upset, ask yourself if the

thoughts are correct, realistic or helpful at this time.

Find helpful alternatives

If the thought isn't based on the facts, or realistic or helpful, try replacing it with a more helpful one.

This may help you feel calmer and less worried. Coach yourself For thoughts to be helpful

they need to be balanced and believable.

Encourage yourself through difficulties, rather than undermining yourself.

Learn to be kind to yourself. Counsellors can teach you these techniques.

In highly stressful situations, thoughts

happen very quickly and you may not even be aware of them.

Your thoughts at this time can be unbalanced and unrealistic - that is, they may be overly negative, exaggerate your problems and underestimate your ability to manage your emotions.

This can leave you feeling more upset and

finding it even harder to cope.

Slide 25 Your Coping Toolbox (Cont.)

12. Be realistic

A common belief is that the most important thing in coping with cancer is staying positive.

While it can help to be optimistic, this doesn't mean denying the reality

that cancer is serious or frightening. Trying to put on a brave face all the time and avoiding anything negative is hard work, drains energy, and generally doesn't work well because the negative thoughts just keep coming back.

Pressure to be positive all the time can lead to people being afraid to discuss fears and

feelings, which can make problems worse.

Try to be realistic about what is happening and talk to someone about your fears and concerns so you can better deal with them.

Explaining your fears and concerns to those around you may also help you get the support you need.

Slide 26 Your Coping Toolbox (Cont.)

13 Deal with recurring difficult thoughts

It is natural for people affected by cancer to find themselves going over and over the same distressing thoughts about the past or future. Ignoring these thoughts or trying to distract yourself may work well at first, but they will often

return once you are no longer distracted - for example, in bed at night or early in the morning.

o Identify where the thoughts come from - When you notice unwanted thoughts check if they are the result of an underlying belief, such as 'I must do things perfectly at all times', 'the world should be a fair and just

place', 'if I can't do everything I used to do I am useless', 'I am a burden to my loved ones'.

Believing that it is possible to do something, even in the worst situations, is the first step in tackling any problem.

o Imagine what you would say to others - Holding on to recurring

thoughts can lead to sadness. One way to challenge them is to think of someone you love and imagine what you might say to them if they felt the same way.

o Check the reality - Having noticed your thoughts, ask yourself if you are jumping to conclusions or exaggerating the negatives. If so, is there

something you can do to change the situation or improve it?

o Acknowledge small achievements - Check if you are focusing on the difficult things and ignoring the little achievements or happy events that may also be occurring. Sometimes we notice the bad things that happen and don't notice the good. Writing down

three good things that have happened to you each day may help. They don't have to be major events - just the everyday things that often go unrecognised.

o Practice letting your thoughts come and go - Thoughts are fleeting. Some we notice and many we don't. Practice letting your thoughts come and go without

getting caught up in them, just like clouds floating across the sky.

Slide 27 Your Coping Toolbox (Cont.)

14. Take your time

Even with a cancer diagnosis, there is often time to consider your treatment choices. Generally, people make better decisions - and

have fewer regrets later - if they have taken time to make sure they have enough information and considered all the possible consequences.

Ask your health care professionals to provide you with details about your treatment choices and the benefits and side effects of each treatment option.

Social workers can give

you information about financial assistance and community supports that are available.

Slide 28 Your Coping Toolbox (Cont.)

15. Write down your options

Organising your thoughts on paper can be easier than trying to do it in your head. Consider

every option available to you.

Slide 29 Your Coping Toolbox (Cont.)

Make sure you have all of the options written down, for example:

Option 1 - only surgery

Option 2 - surgery plus other treatment(s)

Option 3 - only radiation

therapy

Option 4 - active surveillance.

Making decisions

During cancer and treatment you are likely to be faced with the challenge of making difficult decisions. These could include the choice of treatment, how to involve or care for your family, returning to work, and what to do about finances.

List what is important to you

Write down all the pros and cons of each option and consider how important each of these are to you.

You could rate how important each point is on a scale of 1-5, with five being very important and one being least important.

To determine how important a point is, look at how it affects you and others in both the short and long term. Consider the burdens and the benefits of each option.

Talk it over

Talk through the options with someone close to you, like your partner or a close friend. As most

decisions will affect others in your life, it's also important to talk it through with people who will be affected so that their opinions are considered.

Get expert advice

Find out all the facts first, then review your options and the points for and against each one

with specialists in that area, for example, someone in your treatment team, a financial or legal advisor or a counsellor. Being certain of the facts may make the decision and consequences less overwhelming.

Expect to experience doubts

Being unsure does not mean you have taken the wrong path. Reassure yourself that you made the best decision you could with the information you had at the time. Also, decisions are not always final - it may be possible to change your mind even after you have already started down a particular path.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking

their doctor for a second opinion, but specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person.

You can get a second opinion even if you have started treatment or still want to be treated by your first doctor.

Alternatively, you may decide you would prefer to be treated by the doctor who provided the second opinion.

Slide 30 Your Coping Toolbox (Cont.)

16 Telling Others

Sharing news of your diagnosis can be difficult. You may feel

uncomfortable talking about personal matters, or unsure how family and friends will react. You might want to protect your loved ones, but sharing the news can bring you closer together.

Should I tell others?

You will need to decide who you want to tell about the cancer

diagnosis. It's up to you how much detail you give, but hiding your diagnosis probably won't work.

Sooner or later, family and friends will learn that you have cancer either through changes in your appearance or by hearing it from others.

Telling others can also help prevent mis-understandings, put you

in control of what information is given out and allow those who care about you to support you.

Telling different people repeatedly about a cancer diagnosis can be emotionally draining.

It may help to ask a trusted friend or family member to pass on the information and then provide regular updates via weekly phone calls or

emails.

Slide 31 Your Coping Toolbox (Cont.)

The others in your life

How do I tell others?

Telling others about a cancer diagnosis can be difficult but a little preparation can help:

o When you feel ready, decide who to tell and

what you want to say.

o Think of answers to possible questions but only answer if you feel comfortable. You don't have to share every detail.

o Choose a quiet time and place.

o Accept that the person you are telling may get upset. You may find yourself comforting them,

even though you are the sick one.

o Call the Cancer Helpline if you find the prospect of telling people too overwhelming. You may just need to find the right words.

o Ask for help - family or friends could tell others if you can't.

Ksenia's story

"Personally, I feel guilty if I vent or put my problems onto other people. But it's important to know that you are going through an extremely difficult time and that your real friends and the people that love you are strong enough to take on your negativity and feelings of worthlessness.

My friends provided an emotional support guarantee. Often when I had appointments, a friend would say, "I'll call you this evening to see how you went". That one line kept me going all day.

My other friend sent me a card every round of chemo with an inspirational quote, so every three weeks I

would get a card in the mail. I began to look forward to getting them and it made my cancer journey a whole lot more manageable."

Sharing your anxiety and fear may also help you feel stronger. If you already communicate well with certain family members or friends, develop this bond. You

may find that talking about cancer is not as difficult as you had first thought. Sometimes you may feel that nobody understands what you're going through. At a time when you need support, try not to shut others out.

Cancer Survivor Dani said, "People usually don't mean to make things worse. Their

reactions are likely to come from their own difficulties in handling feelings such as fear and anxiety, or from uncertainty about what to do or say."

Slide 32 Video Clip - Peg's Story

This page intentionally blank

Slide 33 Other People's Reactions

Sometimes you may come up against reactions from family and friends that seem insensitive or uncaring.

Some people may avoid or withdraw from you, some may appear too positive or make light of your situation. These reactions may make you

feel hurt, angry or frustrated.

Try not to take their reactions as a sign that they don't care. It may be that they need more time to take in your diagnosis before they are ready to face it.

Cancer is difficult for everyone it affects. Your family also needs to adjust to the diagnosis.

Family members may deal with their feelings in a different way to you.

Your family may experience similar anxieties and need as much information, support and advice as you.

Family members might express their own fear about the diagnosis, at the possibility of losing you, and at their inability

to do anything about the disease.

They may also worry about how the illness will change their lives.

It might help family members having difficulty dealing with your diagnosis to contact a counsellor.

When friends stay away

Cancer can change friendships. Some friends handle it well; others cut off all contact. Friends stay away for different reasons.

They may not be able to cope with their feelings or they may not know how to respond to changes in your appearance.

Your friends may still

care for you, even if they stay away.

If you think that awkwardness rather than fear is keeping a friend from visiting, call them to ease the way.

Remember that you can't always know or understand all the reasons why some people avoid you.

You may find that talking

about your illness helps everyone cope with it better.

o Make time to talk. Don't wait for the 'right' time - it may never come.

o Don't fall into the trap of thinking, 'if they really cared they would know what I need'. They are not mind-readers.

o Be honest about your thoughts and feelings

even if it is upsetting.

- Focus on understanding each other, as this is more important, at least initially, than trying to solve the problem.

- Really listen to what the other person has to say, putting aside your own thoughts and judgments, to try to understand where they are coming from.

o Talk openly about what is happening and what you need, and make some specific suggestions. For example, you may like someone to drive you or keep you company at the doctors.

Slide 34 Talking to kids about cancer

See the handout

Slide 35 Sharing Without Talking

Your own physical health and emotions could fluctuate during and after your treatment. Sometime it's hard to let your friends and family know how you're feeling and they may find it hard to ask.

If you are having trouble talking about how you

feel, you can try sharing your feelings without talking by keeping a journal, or blog. Some people keep two journals, one private and one to share with others.

You could be creative through making music, drawing or doing crafts.

Use an emotions thermometer to show those close to you how you are feeling each day.

The Emotions Thermometer

(Refer to Handout)

An emotions thermometer is a simple tool that allows you to show how you're feeling every day. You can make one yourself and if you have kids, ask them to help.

Decide on the feelings you want on the

thermometer, for example, stress, fear, anger or sadness.

Put it up in a place where everyone can see it, such as the fridge. Attach a pointer, like a magnet that can be moved each day to indicate how you are feeling.

"Today I feel I need a hug

- I need some space
- I'm tired
- I'm happy
- I'm feeling great"

Even though family and friends can be there to help, many people still find it hard to ask for and accept support.

When you are facing the extra demands of cancer,

your support network can make an enormous difference. And family and friends can feel helpless and shut out if they are not allowed to provide support.

Offers of help

Be aware that not everyone will be able to help in the same way. Some people will be

comfortable talking about the cancer and comforting you if you are upset.

However, other people may not be as good with words or strong feelings.

They might prefer to support you in practical ways, such as helping with meals, transport or work around the home.

Let people know what

they can do to help and allow them to choose activities that match their abilities.

Slide 36 Getting Support

Different ways people can help

o Giving practical help - for example, driving to appointments, sharing an after-school roster, providing company, shopping, making meals, helping you exercise.

o Having fun, getting you out and about, not

talking about your worries.

- o Keeping others informed, screening calls and emails, acting as a gatekeeper or support coordinator.
- o Listening without trying to solve your problems.

John M. Braaten in his book *'The Greatest Wonder Of All'* tells of 15-year-old Douglas Maurer of Creve Coeur, Missouri.

Douglas had been feeling bad for several days. Mrs. Maurer took Douglas to the hospital in St. Louis where he was diagnosed as having leukaemia.

The doctors told him in frank terms about his disease. They said that for the next three years, he would have to undergo chemotherapy.

They didn't sugar-coat the side effects. They told Douglas he would go bald and that his body would may possibly bloat.

Upon learning this, he went into a deep

depression.

His aunt called a floral shop to send Douglas an arrangement of flowers.

She told the clerk that it was for her teenage nephew who had leukaemia.

When the flowers arrived at the hospital, they were beautiful.

Douglas read the card from his aunt without

emotion. Then he noticed a second card.

It said: *"Douglas - I took your order. I work at Brix Florist. I had leukaemia when I was seven years old. I'm 22 years old now. Good Luck. My heart goes out to you. Sincerely, Laura Bradley."*

His face lit up. "Oh wow!" he said.

It's interesting: Douglas Maurer was in a hospital filled with millions of dollars of the most sophisticated technological equipment. He was being treated by expert doctors and nurses with competent medical training.

But it was a sales clerk in a flower shop, a young woman making $170 a week, who - by taking the

time to care, and by being willing to go with what her heart told her to do - gave Douglas hope and the will to carry on..

Slide 37 Caring For Someone With Cancer Video Clip 6

This page intentionally blank

Slide 37 Caring For Someone With Cancer Video Summary

INTERACTION: Does anyone wish to share your ideas on how we can help or how you have been helped?

Slide 39 Caring For Someone With Cancer

Here is a list of some and a repeat of other ways to show that you care.

o Become informed - Learn about the cancer and its treatment. This will help you understand what the person is facing. But be careful about offering advice.

o Be around - They'll feel less isolated and know you care. If you are not there in person, check in by phone, text or email.

o Offer to go with them to appointments - You can take part in the discussion, take notes or simply listen.

o Provide practical help - Take the kids to school, provide a meal, help with

the house or yard, or offer to drive them to appointments.

o Try not to do too much or take over - Give the person the opportunity to do things for themselves to maintain a sense of normality.

They may appreciate the chance to be useful and connected to what is important, such as reading to the kids, even

if they can't do as much physically.

o Keep them involved - Even if your family member or friend is in hospital or home in bed, they can still take part in discussions and make decisions about day-to-day life, such as what is happening at school or work.

o Look after yourself - Give yourself time to rest

as well as time away from the person with cancer. You need to look after your health if you're going to give support. Don't underestimate the emotional impact of supporting someone through cancer.

Slide 40 Caring For Someone With Cancer - Video (Mary Ann)

This page intentionally blank

Slide 41 Changing Roles and Routines

When someone is diagnosed with cancer, family roles and routines can change. Don't try to do everything you used to do.

These tips may help you cope:

o Relax housekeeping standards.

o Prepare simpler

meals.

o Ask the children to help more around the house.

o Accept offers of help, for example, with cooking shopping, transport and other household tasks.

o Ask one person to coordinate help from family and friends.

o Think about joining a support group - everyone

needs support and groups are available for children, spouses and carers.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role.

There are also many organisations that can provide you with

information and support, such as Carers Australia, the national body representing carers in Australia. Call 1800 242 636 or visit www.carersaustralia.com.au for more information.

Slide 42 Website

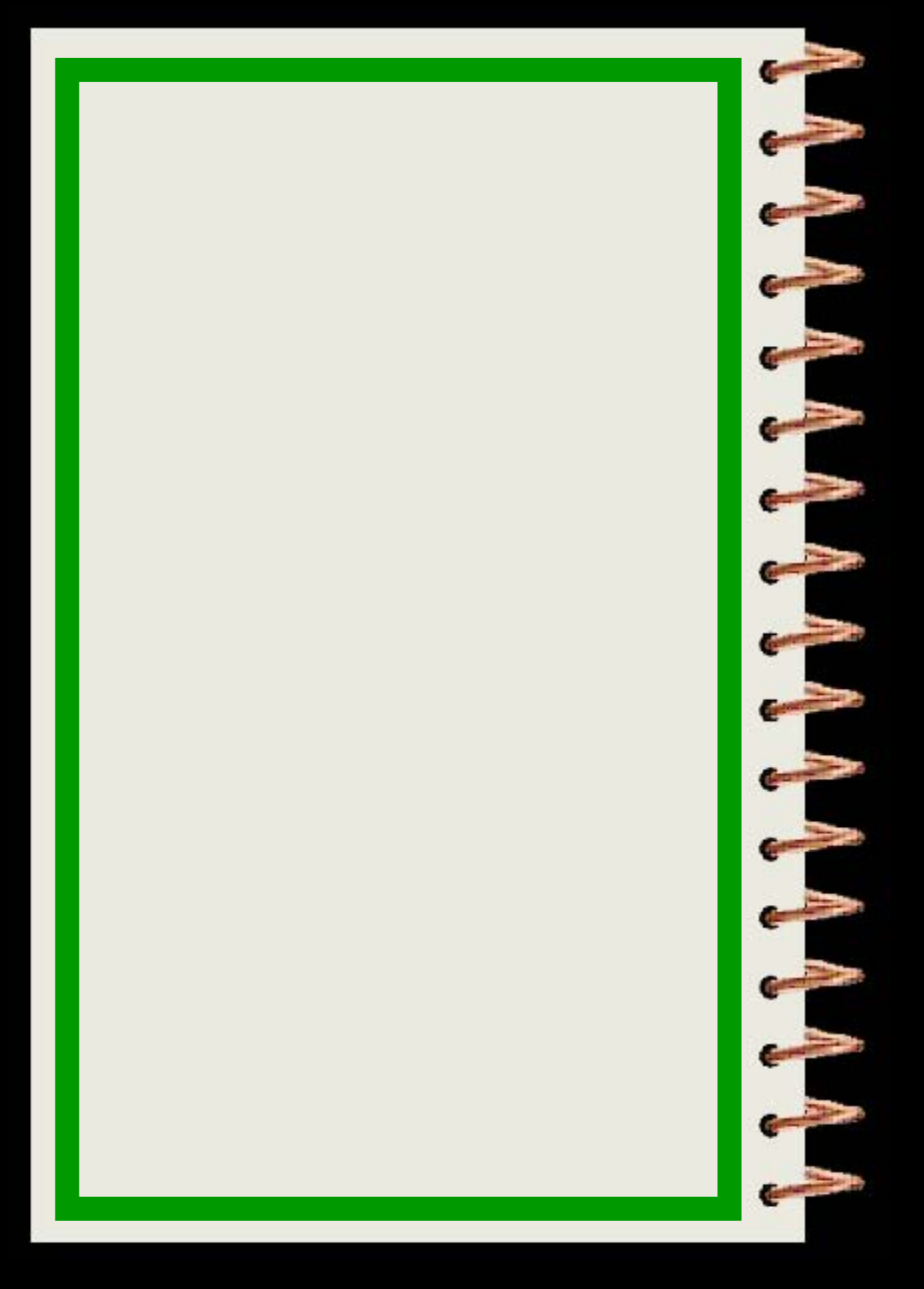
The internet has many useful resources, although not all websites are reliable. The websites linked from our website are good sources of support and information.

Slide 43 Question Time

This page intentionally blank

This page intentionally blank

This page intentionally blank



A seminar with Lionel Hartley, PhD

Surviving & Thriving *with* Cancer

Program:

- Dealing With the Diagnosis
- Common Reactions & Feelings
- Physical Effects of Cancer/Treatments
- Combating Fatigue
- Coping with Pain
- Adjusting to Changed Body Image
- Sexuality, Intimacy and Cancer
- The 16 Tools for Your Coping Toolbox
- Other People's Reactions
- Talking to Kids about Cancer
- Sharing Without Talking
- Getting Support
- Caring For Someone With Cancer
- Changing Roles and Routines
- Finding Hope
- Question Time

www.lrhartley.com/cancer

HERE at this venue

Surviving and Thriving with Cancer

Copyright prevents including this video on the www.

Who is your speaker for today?

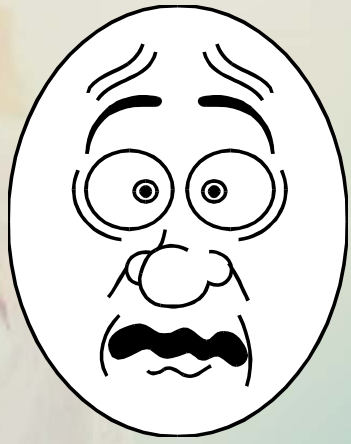
Lionel Hartley, author, radio broadcaster, public speaker and retired sociologist.
He was a Lifestyle Educator and Family-life Counsellor for three decades.
He is a parent with three grown children, a grandparent, and has been married to Rosemary for over 40 years.

Lionel D C Hartley, DipAdmin(NZIM), HonDip (DramArt), DipTheol (SDB), RGN (Psy, PsyPaed, Admin, Nutn), DipBusLaw, DipEcon, DipAccy, BA (Lit), MA, PhD [etc.]

www.hartleyonline.blogspot.com

Dealing With The Diagnosis

- **Feelings you may experience**
  - **Fear**
  - **Anger**
  - **Disbelief**
  - **Sadness**
  - **Guilt**
  - **Regret**
  - **Loneliness**
  - **Loss of Control**
  - **Distress**
  - **Worry**

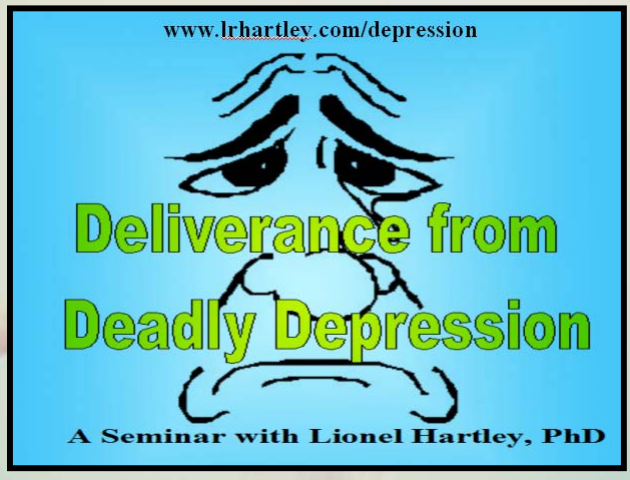


Finding Hope

www.lrhartley.com/cancer

5

Feeling down or depressed?



2:30pm 23rd February

www.lrhartley.com/cancer

6

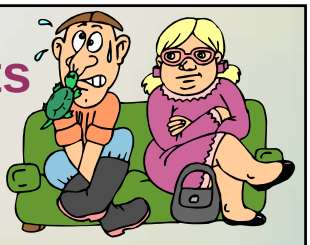
Physical Effects

1. **Fatigue**

Combating Fatigue

- **Schedule**
- **Exercise**
- **Sleep patterns**
- **Nap**
- **Fresh Air**

Physical Effects



1. **Fatigue**
2. **Pain**

Cancer survivor Pete says, "I found the decision to take morphine regularly difficult. Having made it, I have been taking the slow-release tablets for 18 months with no appreciable side effects. Without the morphine, the pain would be too debilitating for me to continue doing all the things I do now."

Physical Effects

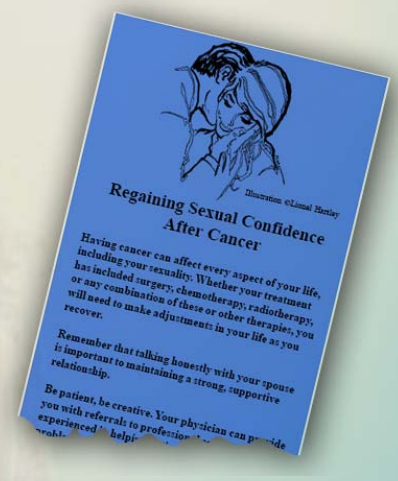
1. Fatigue
2. Pain
3. Changing Body Image

1:30pm 27th July

- 1:30pm - 3:00pm Multimedia Seminar
- 3:00pm Free Afternoon Tea
- 3:15pm – 5:00pm Interactive Workshop

Building Self Esteem & Confidence

Sexuality, Intimacy and Cancer


Regaining Sexual Confidence
After Cancer
Having cancer can affect every aspect of your life, including your sexuality. Whether your treatment has included surgery, chemotherapy, radiotherapy, or any combination of these or other therapies, you will need to make adjustments in your life as you recover.
Remember that talking honestly with your spouse is important to maintaining a strong, supportive relationship.
Be patient, be creative. Your physician can

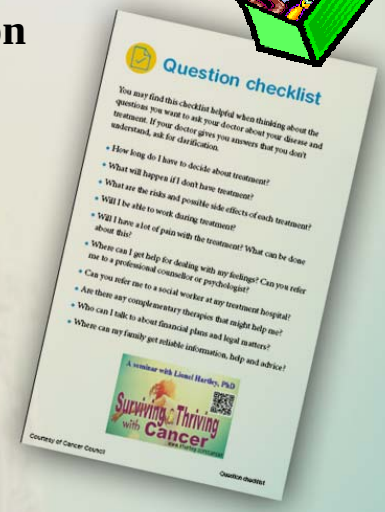
www.lrhartley.com/cancer 11

Your Coping Toolbox

www.lrhartley.com/cancer 12

Your Coping Toolbox

1. Gathering information


Question checklist
You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.
• How long do I have to decide about treatment?
• What will happen if I don't have treatment?
• What are the risks and possible side effects of each treatment?
• Will I be able to work during treatment?
• Will I have a lot of pain with the treatment? What can be done about this?
• Where can I get help for dealing with my feelings? Can you refer me to a professional counsellor or psychologist?
• Can you refer me to a social worker at my treatment hospital?
• Are there any complementary therapies that might help me?
• Who can I talk to about financial plans and legal matters?
• Where can my family get reliable information, help and advice?
A seminar with Lionel Hartley, PhD
Surviving & Thriving with Cancer
Courtesy of Cancer Council

www.lrhartley.com/cancer

13

Your Coping Toolbox

1. Gathering information
2. **Organise and update your affairs**

www.lrhartley.com/cancer

14

Your Coping Toolbox

1. Gathering information
2. Organise and update your affairs
3. **Looking after yourself**

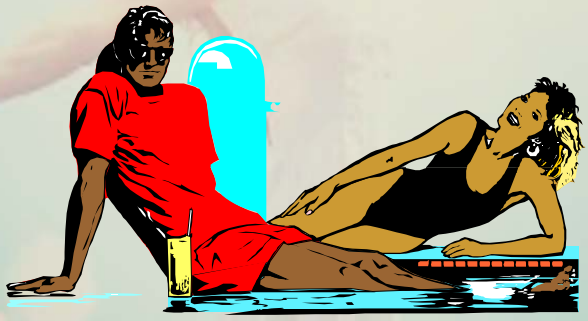
Healthy Group 4 Life

Every Thursday
9:30am - 11:30am
(Except School Holidays)
See www.lrhartley.com/activity

1. **Eat Well** 2. **Be active**

Your Coping Toolbox

1. Gathering information
2. Organise and update your affairs
3. Looking after yourself
4. **Make time for yourself**



Your Coping Toolbox

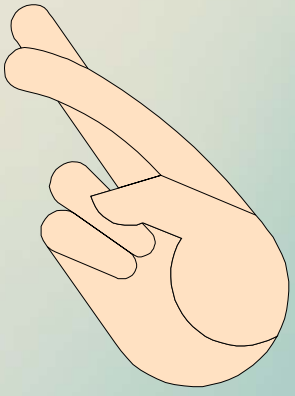
1. Gathering information
2. Organise and update your affairs
3. Looking after yourself
4. Make time for yourself
5. **Deal with feelings**

Your Coping Toolbox

1. Gathering information
2. Organise and update your affairs
3. Looking after yourself
4. Make time for yourself
5. Deal with feelings
6. **Sort out issues**

Your Coping Toolbox

1. Gathering information
2. Organise and update your affairs
3. Looking after yourself
4. Make time for yourself
5. Deal with feelings
6. Sort out issues
7. **Sort out priorities**

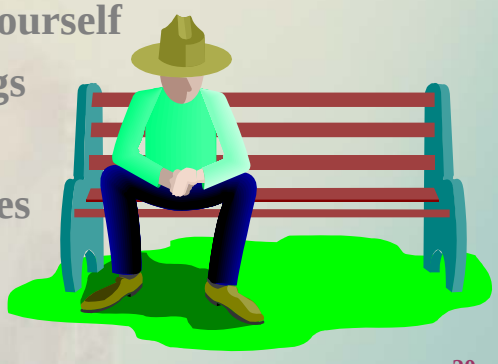


www.lrhartley.com/cancer

19

Your Coping Toolbox

1. Gathering information
2. Organise and update your affairs
3. Looking after yourself
4. Make time for yourself
5. Deal with feelings
6. Sort out issues
7. Sort out priorities
8. **Stay connected**



www.lrhartley.com/cancer

20

Your Coping Toolbox

1. Gathering information
2. Organise and update your affairs
3. Looking after yourself
4. Make time for yourself
5. Deal with feelings
6. Sort out issues
7. Sort out priorities
8. Stay connected
9. **Tap into spiritual beliefs**

Your Coping Toolbox

9. **Tap into spiritual beliefs**

Cancer is so limited.
Cancer cannot cripple love,
Cancer cannot shatter hope,
Cancer cannot corrode faith,
Cancer cannot eat away peace,
Cancer cannot destroy confidence,
Cancer cannot kill friendship,
Cancer cannot shut out memories,
Cancer cannot silence courage,
Cancer cannot reduce eternal life,
Cancer cannot quench the Spirit,
Cancer cannot lessen the Power of the resurrection.

Your Coping Toolbox

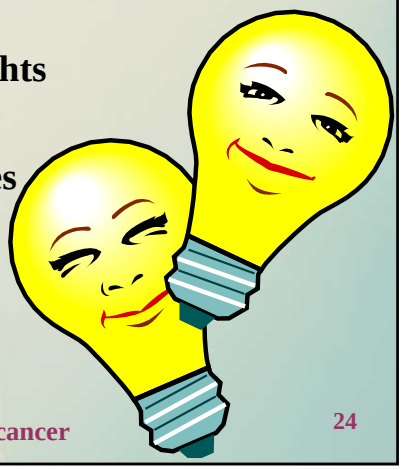
9. Tap into spiritual beliefs
10. **Recognise signs of stress and anxiety**

7:30pm Monday
October 4th
or
2:30pm Saturday
October 26th

www.lrhartley.com/anxiety

Your Coping Toolbox

9. Tap into spiritual beliefs
10. Recognise signs of stress and anxiety
11. **Notice your thinking**
    1. **Write down your thoughts**
    2. **Check your thoughts**
    3. **Find helpful alternatives**



Your Coping Toolbox

9. Tap into spiritual beliefs
10. Recognise signs of stress and anxiety
11. Notice your thinking
12. **Be realistic**

Your Coping Toolbox

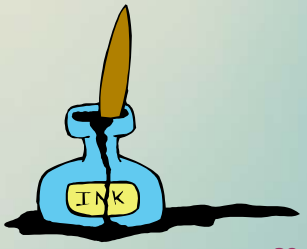
9. Tap into spiritual beliefs
10. Recognise signs of stress and anxiety
11. Notice your thinking
12. Be realistic
13. **Deal with recurring difficult thoughts**
    1. **Identify where the thoughts come from**
    2. **Imagine what you would say to others**
    3. **Check the reality**
    4. **Acknowledge small achievements**
    5. **Practice letting your thoughts come and go**

Your Coping Toolbox

9. Tap into spiritual beliefs
10. Recognise signs of stress and anxiety
11. Notice your thinking
12. Be realistic
13. Deal with recurring difficult thoughts
14. **Take your time**

Your Coping Toolbox

9. Tap into spiritual beliefs
10. Recognise signs of stress and anxiety
11. Notice your thinking
12. Be realistic
13. Deal with recurring difficult thoughts
14. Take your time
15. **Write down your options**



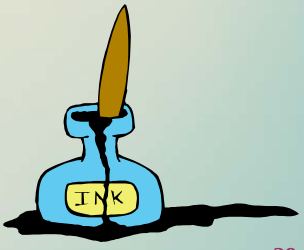
Your Coping Toolbox

15. Write down your options

Example:

Option 1 – only surgery
Option 2 – surgery plus other treatment(s)
Option 3 – only radiation therapy
Option 4 – active surveillance

a. Making decisions
b. List what is important to you
c. Talk it over
d. Get expert advice
e. Expect to experience doubts
f. A second opinion



Your Coping Toolbox

9. Tap into spiritual beliefs
10. Recognise signs of stress and anxiety
11. Notice your thinking
12. Be realistic
13. Deal with recurring difficult thoughts
14. Take your time
15. Write down your options
16. Telling Others

Your Coping Toolbox

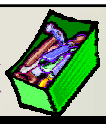
16. Telling Others - How do I tell others?

a. When you feel ready, decide who to tell and what you want to say.
b. Think of answers to possible questions
c. Choose a quiet time and place.
d. Accept that the listener may get upset.
e. Call the Cancer Helpline if you need help
f. Ask for help – family or friends could tell others if you can't.

Cancer Council Helpline 13 11 20

Ksenia's story

Your Coping Toolbox

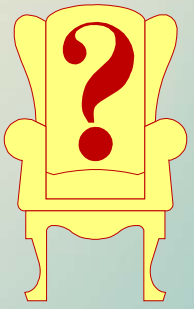


Copyright prevents including this video on the www.

Other People's Reactions

When friends stay away

- **Make time to talk**
- **Don't fall into the trap of mind-reading**
- **Be honest about your thoughts and feelings**
- **Focus on understanding each other**
- **Really listen to the other person**
- **Talk openly**
  - **about what is happening**
  - **about what you need**
  - **make some specific suggestions**



www.lrhartley.com/cancer

33

Talking to kids about cancer

www.lrhartley.com/cancer

34

Talking to kids about cancer

Sharing Without Talking:

The Emotions Thermometer

www.lrhartley.com/cancer

35

Getting Support

Different ways people can help

- **Giving practical help**
- **Having fun together**
- **Acting as a gatekeeper or coordinator**
- **Listening without trying to solve problems**

www.lrhartley.com/cancer

36

Caring For Someone With Cancer

- **Video Clip 6**

Copyright prevents including this video on the www.

Caring For Someone With Cancer

Revision:

- **Listen up**
- **Shuttle Service**
- **Take Notes**
- **Good Housekeeping,**
- **Don't Fake It**
- **Support Yourself**
- **Give it a Break**
- **Live Life to the Full**

Caring For Someone With Cancer

- **Become informed**
- **Be around**
- **Offer to go with them to appointments**
- **Provide practical help**
- **Try not to do too much or take over**
- **Keep them involved**
- **Look after yourself**

Caring For Someone With Cancer

Copyright prevents including this video on the www.

Changing Roles and Routines

Tips to help you cope:

- **Relax housekeeping standards**
- **Prepare simpler meals**
- **Ask the children to help more**
- **Accept offers of help**
- **Ask one person to coordinate help**
- **Think about joining a support group**

www.lrhartley.com

41

More Resources

www.lrhartley.com/cancer

42

Question Time

www.lrhartley.com/cancer

43

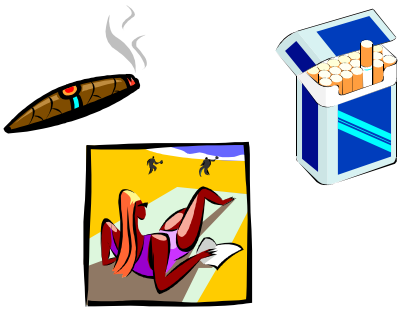
What are the risk factors for cancer?

Risk factors are things that increase your chances of getting a disease. Certain risk factors, like age and family medical history, are not controllable. Other risk factors, like smoking or eating a high fat diet, are things we can control.

Major scientifically proven risk factors:

- Smoking (cigarettes, cigars, smokeless tobacco, marijuana, AND second hand smoke)
- Obesity
- Ultraviolet light (from the sun or tanning beds)
- Alcohol consumption

Tobacco use, diet, infectious disease, and exposure to chemicals or radiation cause approximately 75% of all cancer cases.



Other scientifically proven risk factors:

- Inherited gene (mutation change)
- Environmental Pollutants (pesticides, burning fossil fuels)
- Ionizing radiation (x-rays, sun, and radon)
- Viruses (HPV, hepatitis B and C, Epstein Barr)

What are the signs and symptoms

Although specific symptoms depend on the kind of cancer, there are some general warning signs and symptoms of cancer that you should be aware of. These include:

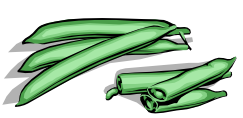
- Unexplained weight loss
- Fever
- Tiredness
- Pain

Other common symptoms to report to your doctor:

- Change in bowel habits or bladder function
- Sores that do not heal
- Unusual bleeding or discharge
- Lump in the breast or other part of the body.
- Indigestion or difficulty swallowing
- Change in wart or size of a mole
- Nagging cough

You can protect yourself…..but how?

EAT A HEALTHY DIET— **Vegetables, fruits, whole grains and beans protect you from developing cancer!!** Also, limit consumption of fat, salt, red meat, and meat cooked at high temperatures or in direct flame.



Salubrity ™ Seminars
Salubrity — Living Life to the Full
<www.geocities.com/info_seminars>

Get regular exercise, avoid tanning beds, use sunscreen, and limit alcohol consumption. **But most importantly**…. Do not smoke!

A seminar with Lionel Hartley, PhD

Surviving & Thriving with Cancer

www.lrhartley.com/cancer

1. Gathering _____

2. _____ and update your affairs

3. Looking after _____

4. Make _____ for yourself

5. Deal with _____

6. Sort out _____

7. Sort out _____

8. _____ connected

Feelings:

Fear
Anger
Disbelief
Sadness
Guilt

9. Tap into _____ beliefs

10. _____ signs of stress and anxiety

11. Notice your _____

12. Be _____

13 Deal with recurring difficult _____

14. Take your _____

15. Write down your _____

16. _____ Others

Regret
Loneliness
Loss of Control
Distress
Worry

(Answers on www.lrhartley.com/cancer)

Robert Fulghum writes, “A man I know found out last year he had terminal cancer. He was a doctor and knew about dying, and he didn't want to make his family and friends suffer through that with him. So he kept his secret. And died.

Everybody said how brave he was to bear his suffering in silence and not tell everybody, and so on and so forth.

But privately his family and friends said how angry they were that he didn't need them, didn't trust their strength. And it hurt that he didn't say goodbye.”

Cancer is so limited (Anonymous)

Cancer cannot cripple love,
Cancer cannot shatter hope,
Cancer cannot corrode faith,
Cancer cannot eat away peace,
Cancer cannot destroy confidence,
Cancer cannot kill friendship,
Cancer cannot shut out memories,
Cancer cannot silence courage,
Cancer cannot reduce eternal life,
Cancer cannot quench the Spirit,
Cancer cannot lessen
the Power of the resurrection.

Regaining Sexual Confidence After Cancer

Having cancer can affect every aspect of your life, including your sexuality. Whether your treatment has included surgery, chemotherapy, radiotherapy, or any combination of these or other therapies, you will need to make adjustments in your life as you recover.

Remember that talking honestly with your spouse is important to maintaining a strong, supportive relationship.

Be patient, be creative. Your physician can provide you with referrals to professional counsellors experienced in helping patients who have sexual problems following treatment. The pleasure of sexual closeness enhances quality of life and can be adapted, no matter what treatment has been used. Talk with your doctor or nurse about any restrictions you may have.

This seminar handout contains suggestions to help you and your spouse regain sexual closeness.

Before You Resume Sexual Activity

:} Focus on your physical recovery first. Emphasize nutrition, rest, and a gradual return to regular activity.

:} Include your spouse in all discussions about your care and treatment while you are still in the hospital.

:} Be sure that your hospital discharge instructions include advice about resuming sexual activity. If your nurse or doctor doesn't mention it, feel free to ask.

:} Use birth control, if indicated by your doctor or nurse.

:} You've been through a lot. It may take some time before you are interested in sex again. Be patient with yourself.

:} Report any unusual bleeding, discharge, fever, or pain to your doctor or nurse.

When You Feel Ready

:} Remember that self-concept and sexuality are linked, so emphasize the positive aspects of your appearance and personality.

:} Wear comfortable, attractive lounging clothes and perhaps perfume or cologne, not only to arouse your spouse, but to feel good about yourself.

:} Set the stage for sexual contact by choosing a time when both you and your spouse are rested and free from distractions.

:} A warm shower together allows a couple to begin foreplay in a relaxed way.

:} Chocolates, fruit pieces, or chocolate biscuits to share, with candlelight and music can add to a romantic mood.

:} Mutual massage, not only of the genital area, but of the neck, chest, buttocks, thighs and feet, can be stimulating to both partners.

:} Experiment with positions until you find one that is most comfortable for you. If you are feeling fatigued, try positions that require minimal exertion.

:} Use a water-soluble lubricant (such as K-Y Jelly, Astroglide, or Replens to increase vaginal moisture.
Do not use petroleum jelly (such as Vaseline).

:} Use prescribed pain medication or muscle relaxants, if necessary, to make sexual activity more comfortable.

:} Conserve energy for sexual activity, perhaps by giving certain household chores to others.

:} Explore alternate ways of expressing physical love.

:} Communicate needs and desires so that sexual activity is pleasurable for both you and your spouse.

:} Consider joining a support group, where you will find couples with concerns similar to yours.

:} Consider sexual rehabilitation or sexual counselling if there are physical or psychological barriers that do not resolve with time.

:} Most important, remember that with some effort by you and your spouse, your sexual life can return to what it was ...or maybe it can be even better.

Changes

Our lives once had a rhythm
The hectic pace of a busy life
Jobs, travel, children, errands
But always able to return
To the comfort of each other

Our rhythm disrupted by illness
The frantic pace of survival
Hospitals, surgery, chemo, radiation
Afraid we would never return
To the comfort of each other

A new rhythm out of the chaos
The slow pace back to normalcy
Communication, time, patience, love
The journey back and our return
To the comfort of each other

— by Sue Grier

(Reprinted in a brochure by the University of Pittsburgh 2003)

A seminar with Lionel Hartley, PhD

www.lrhartley.com/cancer